White, W. L. (2001). Family perspectives on medication-assisted recovery: An interview with Rolando Torres. Posted at www.facesandvoicesofrecovery.org and www.williamwhitepapers.com.

Family Perspectives on Medication-assisted Recovery: An Interview with Rolando Torres

William L. White

Introduction

Lisa Mojer-Torres, prior to her death from cancer on April 4, 2011, was the most visible and effective advocate for medication-assisted treatment and recovery in the United States.

After receiving her J.D. from New York University School of Law, Lisa worked as a civil rights attorney in New York and New Jersey and served as the Consumer and Recovery Advocate for the New Jersey Division of Addiction Services. A leading figure in the new addiction recovery advocacy movement, Lisa was a founding member and first chairperson of Faces and Voices of Recovery and served on the Board of the National Alliance of Methadone Advocates. Her advocacy activities also included congressional testimony, media interviews, presentations at innumerable conferences, serving on multiple advisory boards—including the National Institute of Medicine and the Center for Substance Abuse Treatment—consulting with countless local treatment and recovery support programs, marching in recovery celebration events, and of course, her professional writing—including co-authorship of the monograph *Recovery-Oriented Methadone Maintenance*. In conversations with Lisa's husband Rolando in the months following her death, we spoke of the marked absence of the voices of family members in discussions of methadone maintenance and other forms of medication-assisted treatment of addiction. In the opening days of 2012, I interviewed Rolando about his life with Lisa and his evolving views on medication-assisted treatment and recovery. Like Lisa's, his is a powerful voice, filled with deep insight, great passion, and a bold vision for the future. Please join me in this powerful and deeply moving discussion.

Personal Background

Bill White: Rolando, could you begin by describing your personal background for our readers?

Rolando Torres: Yes. I was born in Puerto Rico and came here when I was four years old. My father came to New York from Puerto Rico in the early 1950s, and my mother soon followed. We lived in the Hunts Point area of the South Bronx, and I stayed there until about 5th grade, at which time my parents found a better place to raise my sister and me. We moved around a lot. There was never a stable place, and we were in some pretty bad neighborhoods. I went to schools in the South Bronx and the East Bronx, graduating in 1970. I then went to Herbert H. Lehman College in '70 and graduated there in '74. I was previously married for 7 years and had no children in that marriage.

I started law school in 1978 at Rutgers Law School in Newark in 1982. I passed the New Jersey bar exam and was admitted to the Bar in New Jersey in 1984. I then held various positions, including working as a Public Defender and rising to the level of Director of Civil Rights and thereafter holding various high-level positions within state government. I left government work in 2008 with hopes of earning more money in private legal practice. Eight days after I left state government, my wife was diagnosed with Stage 3 Ovarian Cancer. That was May of 2008. From May 2008 to her passing in April of 2011, I practiced law part-time. I took care of the kids and took care of her. Now, I'm trying to piece my life back together and adapt to a new role as a single father with all the day-to-day challenges that entails.

Courtship and Marriage

Bill White: You were married to the person who, for many people, was the public face of medication-assisted recovery and advocacy in the United States. How and when did you and Lisa first meet?

Rolando Torres: We met in 1984. A friend introduced us thinking that, with our backgrounds as lawyers, we might hit it off. Lisa was very beautiful and very intelligent. I fell head over heels in love with her and was walking on clouds for a great deal of that time.

Bill White: Was Lisa in recovery when you were married?

Rolando Torres: We weren't married until 1987. In '84, I think she was struggling with the issue of her addiction, but I did not know that until my friend dropped the big bomb that she was on methadone maintenance.

Evolving Views on Addiction/Treatment/Recovery

Bill White: What was your first reaction to that discovery?

Rolando Torres: My first reaction was devastation. Totally! Emotionally, I went from walking on clouds to walking on glass. It was a difficult time because I had to then confront her by asking what the situation was. I had to really dig down deep and think. I was Don Quixote for all intentions. I think Lisa could have told me that she was a serial killer, and I probably would have just said, "We'll get through this, honey. We'll just run to Brazil and start a new life." I was so in love with her. It was tough, but I just put this issue in an emotional parking lot.

You know, the interesting thing about this is that I grew up around multiple addictions, and I had friends that actually died from overdoses of heroin. I personally escaped all of that, and I had also seen a lot of people overcome addiction positively. And so, rationally, I weighed out everything and I said, "You know what? I'm going take this ride" and boy, was it a bumpy ride for a while.

Bill White: Rolando, it's my understanding that Lisa had tried some alternatives before methadone treatment?

Rolando Torres: Yes, she had really tried to use the abstinence route, but that never worked for her long-term. She had slips, and the cravings paralyzed her life. She was just one of those people that for all purposes, had given her life to God and done everything possible in her power. She could not live with the cravings to use heroin. Furthermore, she was always frightened of detoxification and the pain of that process. At that point, she enrolled in methadone maintenance at Beth Israel Hospital.

Bill White: What were your early attitudes toward methadone maintenance?

Rolando Torres: My attitude was totally negative; I wanted a clean, drug-free wife. I thought that maybe if we went and became marathon runners or if we did this or that, that perhaps I would be able to cure her. I thought she would be okay if I could just fill the gaps in her life. In retrospect, I miscalculated the odds of my ability to cure Lisa.

Bill White: How did those attitudes change over time? Was there a critical turning point for you?

Rolando Torres: Yes, there was. First of all, we went through everything, and I saw her initially go through the clinic and pick up medication on a daily basis. It was hard to see someone you love go through the indignities of standing in a line

each morning as an "addict" to receive medication. I could not imagine how personally humiliating it was for her. And then we decided to get married in ’87, and she decided that she was going to go into rehab.

She went into one of the best rehabs in the country, and she did it all—worked hard in treatment, grappled with her demons, did meetings, got a sponsor. She did all of those things.

But when she got off methadone, she was lost those first weeks and months. She tried to deal with life without medication, but she had the same difficulties. She finally decided that she should go back on methadone. That was a very difficult time because at that point, I had one foot out the door. She had tried therapy, and it just didn’t work.

Bill White: But there was then a turning point?

Rolando Torres: Yes. Stan Novick, Lisa’s counselor at Beth Israel, met with me and broke it down. He said, “Look, your wife has an addiction, and medication is the best way that she can manage that condition.” He educated me about opioid addiction and the myths and truths about methadone. He did it in a very humane, considerate way. And he told me that if I hung in there, it would be worth the investment.

Bill White: One of the myths about methadone is the perception that stabilized methadone patients get high from the medication they take and are impaired by methadone. Lisa’s life and achievements would seem to refute that.

Rolando Torres: I think that methadone is metabolized differently by everyone. It’s a medication and has side effects like any medication. The clinics don’t do enough to help their patients and families understand what the medication does and the differences between using methadone as a medication as and using heroin as a drug. Lisa was functioning at an exceptional level of performance using methadone as a medication. She finished law school and during that time, she worked as a legal secretary for some of the major law firms in New York City. Methadone was a stabilizing force that enabled her to go back to law school and finish up and achieve all that she achieved afterwards.

During this time, I had very conflicted feelings about my wife being on methadone and all the stigma and negative connotations that brought. So we kept her methadone patient status to ourselves for some time. I had friends and colleagues who never knew. Lisa would leave at 6:30 in the morning to go get her medication. It would break my heart to drive her into the city and see this beautiful, wonderful, intelligent person having to stand on the street in line outside

the clinic in the cold and snow to get her medication. I wish our readers could understand what its like to see somebody you care about who has all the potential in the world grapple with addiction and the indignities that come with methadone treatment.

A Husband's Perspectives on Treatment

Bill White: Lisa shared with me that she had participated in a large public clinic and in an office-based practice. How would you compare those two experiences?

Rolando Torres: When Lisa had progressed to a certain point at her methadone clinic, she was able to move to the office-based practice—a special program that was allowed by the powers that be for a small, select group of patients who were stabilized and viewed as the cream of the crop at the Beth Israel Clinic. The dignity of being treated not as an addict, but as a physician's patient changed the world for Lisa and our family. She went from being diminished, losing her dignity, to being respected and treated like a REAL patient. It made me think of the clinic experience: How can you build someone up if everything you provide them in the way of treatment is inconvenient, demeaning, and costly?

The initial stage of going on methadone and having to take your medication in front of the nurse and all of the other rituals of methadone maintenance are so disrespectful. You can't stand outside and talk to your friends because the clinic doesn't want people congregating in the neighborhood. Of course there are concerns about diversion, but there has to be a way to deal with this and still treat people like they are human beings. After all, the patients through their addiction have already been diminished to a subhuman level. And then in the process of helping that person, the person becomes further dehumanized. Given the issues that you have to deal with to get medication, stay on the program, and deal with the bureaucracy, the term "treatment" seems a misnomer. I don't know if you can call it "treatment."

I do not want to trash all those working within methadone treatment programs here. They are caught in the same stigma-trap that ensnares patients, family members, and policymakers. As long as addiction is viewed as a choice rather than a disease and patients are treated as bad rather than suffering, there is no escape from this trap for any of us. That starting premise affects everything that flows from it. If programs espouse treatment philosophies proclaiming that addiction is a disease, then why are those they serve treated more like criminals than patients? What distinguished Lisa was that she truly understood that she had an illness and would not allow people to treat her as if her addiction was a personal

choice. She took full responsibility for her recovery, but she would not accept for herself, nor would she tolerate from others, blame or contempt for her addiction.

Bill White: From your experience living with someone in medication-assisted recovery, what are your thoughts about how methadone maintenance could be improved?

Rolando Torres: I think office-based treatment of opioid addiction is the answer. In the clinics, counselors and those who administer the methadone often do not believe in methadone. They embrace myths about methadone as much as the public. They don't view it as an effective channel of recovery. They basically view it as a vehicle to temporarily stabilize somebody with the real goal of treatment being to make a person drug-free, which in their thinking means no medication. All counselors do not hold that view, but based on Lisa's experience, many do. The "drug free" emphasis is sort of a one size fits all solution, which in many cases, fails miserably.

Such attitudes are insane: parents having children removed because of being in methadone treatment, judges who are not physicians dictating that a person should get off methadone without any real information or any sense of responsibility for that human being. These bureaucracies are built on a negative stereotype of this medication, what it does to the people who take it, and a misguided view that addiction is a personal choice—despite the scientific evidence that says otherwise. So when you go to an office-based practice, you begin to separate the medication from the person, with the administration of the medication being one thing and the therapeutic element of getting that person to the best possible place they can be being another.

The Need for Family Involvement in Treatment

Bill White: To what extent were you as Lisa's husband involved in her treatment?

Rolando Torres: There was no special education for family members. No one ever called me in to talk about Lisa or how we as a family were doing. It was Lisa who asked Stan Novick to visit and discuss methadone with me. That was not a standard part of treatment. In a sense, it was fortunate that they didn't call me in because I'm not sure that most counselors had the capability to understand the best message to convey to me. My hope is that through Lisa's effort and the articles you wrote with her that new attitudes will emerge as well as expanded support for families. People running methadone treatment programs really need to think about

the messages conveyed to family members about treatment and recovery. But given prevailing attitudes, I'm glad they didn't call me.

Bill White: Families must recover from the impact of addiction, but they must also recover in the face of all this great misunderstanding about the role of medication. Given that you weren't involved in any of that treatment and weren't offered any support, how would you describe your own family recovery process?

Rolando Torres: Well, it was bumpy, literally. It was like going through a road with a lot of potholes. I struggled with her need for medication and her inability to achieve recovery stability without it. And that caused a lot of conflict because I myself had not come to terms with the facts of her condition and understanding that recovery could occur within the context of medication rather than the misguided goal that recovery could occur only without medication. I needed to understand what recovery meant for someone on medication, and to stay out of the way of Lisa's path to recovery. When that happened, I saw Lisa transform from someone who was totally beaten down to someone who had a mission and a passion to come out of the shadows and break the myths surrounding her addiction and the choices around treatment. There was a real transformation when she began to understand the science of her disease and began to educate me about addiction and brain chemistry.

As I said, methadone stabilized Lisa's life, stabilized it efficiently so that she could complete her education, pass two bar exams, and achieve all that she achieved after that. I had as much of a problem coming to grips with Lisa's solution as I did in understanding her addiction.

Bill White: What supports should be offered families of patients in medication-assisted treatment?

Rolando Torres: Most importantly, the family needs to understand the disease and the role of medication in its treatment. We need therapy groups or support groups to talk about the challenges for the person in recovery. It is extremely difficult to understand what it entails for the patient to grapple with all of the issues surrounding addiction and stigma. Education is critical—the same education that that patient gets, the family needs to get. The family needs to sit down and understand what the medicine can and cannot do.

Bill White: What do you think are some of the most important things families need to understand? I've heard you say you're an expert on what not to do.

Rolando Torres: Yes, I screwed it up so many times. I mean, I think it's important for families to understand that if you really love this person, you have to walk the path with them, and the path is not going be easy. You can't talk someone into recovery by simply declaring to them, "You know what? You're an addict, and you really need to get help and you need to get off this medication." People with addictions are already diminished to an extreme point. What they don't need is more shame thrust on them from their families. You can't torture a person who's already struggling. They don't need one more problem.

Bill White: What efforts should be taken to educate or support the children of methadone patients?

Rolando Torres: The needs of children will differ based on the context of parents' lives. Methadone patients come from all social strata. That was the clear message I got when I went with Lisa to her clinic. I used to drive Lisa in and see people who had recently been released from jail and were using again, standing with the rich kids from New York's finest schools, and many others who were struggling with one thing—Addiction. So, you get the sense that it impacts a diversity of people.

It's important to really get to the children. What ends up happening is that the children take on the pressure of whatever the parents are carrying. The children need support, but I do not think we know what the message should be. I think we're at such an early stage in knowing how to deal with families, and yet it is such a critical and important link to recovery. This family component is an important part of the new paradigm of treatment that you and Lisa were working on.

Stigma, Treatment, and the Family

Bill White: Let me take you to the issue of stigma. Could you share the kinds of stigma and discrimination Lisa faced because of her association with methadone maintenance?

Rolando Torres: First of all, personally and as a couple, we were not talking up the fact that Lisa was in recovery. We considered her recovery a personal medical issue. It's basically something that you keep to yourself and try to lead as normal a life as possible. But you're always in dread that somebody's going to say, "Hey, wasn't that your wife I saw in line outside the methadone clinic the other day" or that someone's going to go into your bathroom and find bottles of medication. I

know from that Seinfeld episode that there is this whole group of people that like to go through other people's medicine cabinets.

So there's always a side of you that's extremely guarded about the status of your spouse because you are worried about what someone is thinking about the fact that you are married to someone who is struggling with addiction. And more than that, what are they going to think about the person I love?

Lisa experienced stigma in a lot of ways: just the indignities of her initial treatment, picking up medicine on a daily basis, and having to take it in front of a nurse at the clinic. Subsequently, there was the hardship of trying to get admitted to the New Jersey bar. She passed the New York bar and the New Jersey bar examinations, but New Jersey attempted to put some very onerous restrictions on her just because she was honest about her addiction history. She could have escaped all that by just "lying," but honesty was an important part of her recovery. Those restrictions were imposed in spite of the fact that Lisa had never transgressed the law as an adult and had these wonderful character witnesses. But the fitness committee viewed her past addiction history as a character defect, not a medical condition.

We challenged those onerous restrictions and ultimately the New Jersey Supreme Court ruled in Lisa's favor. The Court removed all of those conditions and allowed her to practice law, but she still had difficulties getting a job. Once she went public with her recovery, everyone wanted her to serve on this committee or that, but they were not offering her paid work as a lawyer.

Bill White: Was it difficult dealing with Lisa's recovery status and her activist role within your extended families?

Rolando Torres: Not as difficult as you might think. We both had small families, and I think everyone was just relieved she had achieved stability in her life and that she was doing such positive things and accomplishing so much. She also was assertive in educating her family about addiction and her pathway of recovery. The Supreme Court decision was a turning point for our family and for Lisa. It was then she realized the pervasiveness of discrimination toward methadone patients and how such discrimination impeded a person's recovery by denigrating them. Patients were not judged for who they were and what they had accomplished; they were judged for being on the medication that brought sanity and stability into their lives. That realization propelled her advocacy. She understood that there was a battle to be fought and that she was going to fight it even if there were not a lot of people willing to join her in this battle. For many years, we supported her work out of our own pockets. There weren't many people standing up and saying, "Hey,

Lisa, let's go out and fight this stigma." Ultimately with Lisa's continued advocacy, stigma became a greater issue in the field.

Bill White: What were your first reactions when Lisa began to go public with her treatment and recovery story?

Rolando Torres: It was crazy for me because I was the guy who was guarding the castle with the keys. She would come home and tell me she was telling her story, and I would turn and leave or go a little crazy because I had a very responsible and important position, and I was always worried about how much people knew about Lisa's recovery from addiction. I never denied that my wife was in recovery, but I was nervous early on about her telling her story. We came to an agreement about how much of that story needed to be told. Ultimately, I realized how important sharing her story was for her and other people, but that realization came late in the game. Eventually, I reluctantly began to understand how important it was to her self-esteem.

Bill White: I've heard you say that there's greater stigma toward methadone in the addiction treatment community than in the larger society. Could you elaborate on that?

Rolando Torres: Yes. Lisa constantly told me stories of the attitudes she encountered from treatment professionals and the outrageous things they would say about methadone. This came from methadone critics, but it also came from those working in methadone treatment. Both groups seemed to know little about the scientific evidence supporting the effectiveness of methadone maintenance. And there was an attitude that methadone patients were still addicts and not worthy of care or counseling. Lisa was part of the fight to keep supportive services in place for people in methadone treatment and to educate the counselors working in methadone clinics.

It seemed to me that the whole counseling field was totally in the dark about methadone treatment. Counselors like Stan Novick were the exceptions in our experience. Lisa would come home and tell me about her experiences, and I came to the conclusion that the field itself did not understand methadone treatment and what it could and could not do. Again, there is a need to separate the understanding of the medication from understanding of the person. They did not seem to understand recovery. One thing Lisa did fight for was the consumer focus—giving the patient choices and understanding what the patient was seeking to gain from the medication.

Bill White: Rolando, what did it mean for Lisa to be able to tell her story in professional and public forums?

Rolando Torres: It was liberating. I think that it gave her power—the sense that her life's journey had meaning. Telling her story and her larger advocacy activities gave her a purpose, particularly when she realized that in telling her story, she was liberating other people to tell their stories.

Lisa's Legacy

Bill White: One of the major projects Lisa worked on the last two years of her life was the monograph that she and I collaborated on together. I was so amazed by her fortitude through that process even on days when she was sick from the cancer treatments. What did that project mean to her?

Rolando Torres: I'm getting emotional here because I realize it was the culmination of her life and her desire to help others. The monograph was a way she could memorialize her life. That work was such an important step for her. She wanted to create a vision or path that could guide people recovering from addiction with the aid of methadone. She knew that the one voice absent in the methadone debate was that of the patients, and her goal was to change that. And, Bill, getting back to stigma, even at the end of her life when she was in great pain, she still had to confront the hospitals' and the physicians' lack of understanding of methadone. Rather than making it easy for her, she still had to fight because no one viewed methadone as a necessary medication. They viewed it as something that someone should really not be on. Even in her cancer treatment, she was stigmatized by certain physicians.

Bill White: What did it mean to you as a family for Lisa to receive such national recognition for her recovery advocacy work?

Rolando Torres: I really didn't absorb it all until she passed. Unfortunately, when she got the award from AATOD (American Association for the Treatment of Opioid Dependence), my father had passed away in Puerto Rico, so I was not able to be with her. I never really got a chance to experience with her the kind of joy that she got and the pride of knowing all the people's lives she touched. But I see now what an enormous impact she had.

Bill White: The voices of family members like yourself have also been absent from public discussion of methadone maintenance treatment in the United States.

Do you think family members have a future role in educating the country about the role of medication in long-term recovery from opioid addiction?

Rolando Torres: Absolutely. Education breeds knowledge, which breeds understanding. I think people who have gone through this experience as a family have a great deal of wisdom to share with other families similarly affected and with addiction professionals and policymakers. Like me, a lot of family members are now experts on what not to do, but we have also learned some things about how to help an addicted family member. We can help move families from the position, "You need to get clean and get off the medication like other people have" to understanding the complexity of addiction and some people's need for a medication-assisted recovery pathway. Some people will be able to recover without methadone and some will not. That's part of the complexity that people need to understand. The methadone debates have been oversimplified on both sides. I think the biggest contribution that Lisa made was to convince people that one solution does not fit everyone. Policymakers, judges, counselors, and family members can all exert their God-like power. It is time we humbled ourselves in the face of the enormous complexity of both addiction and recovery. That complexity is what Lisa wanted all of us to understand.

Bill White: Rolando, thank you for your willingness to discuss Lisa's life and work and the journey you both shared.

Acknowledgement: Support for this interview series is provided by the Great Lakes Addiction Technology Transfer Center (ATTC) through a cooperative agreement from the Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Substance Abuse Treatment (CSAT). The opinions expressed herein are the views of the authors and do not reflect the official position of the Department of Health and Human Services (DHHS), SAMHSA, or CSAT.